

Teleconference

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How HIPAA, FERPA, and Part C IDEA privacy regulations affect newborn hearing screening programs

Dr. Todd Houston.

STEVE RICHARDSON (CDC-EHDI):

On behalf of the Early Hearing Detection and Intervention Program, I'd like to welcome everybody to our presentation on how HIPAA, FERPA, and Part C IDEA privacy regulations affect newborn hearing screening programs

Our presenter today is Dr. Todd Houston. He's Deputy Director of NCHAM at Utah State University. As Dr. Houston makes his presentation, write down any questions you have, and we'll save the time for questions and answers at the end of the presentation.

Now, in order to leave maximum time for the program and questions, we'll compress Dr. Houston's biography into a few short sentences. He's an assistant professor in the department of communicative disorders and deaf education at Utah State University where he develops opportunities in auditory learning and spoken language for children with hearing loss and their families.

He also serves as deputy director of the NCHAM, which is under the direction of Karl White. Prior to joining the faculty at Utah State University, he was the director and chief executive officer of the Alexander Graham Bell Association for the Deaf and Hard of Hearing, AG Bell, located in Washington DC.

With that, I will turn it over to Dr. Houston.

>> **TODD HOUSTON:** Thank you, Steve.

I hope everybody can hear me well.

It's a pleasure to be here today, and I'd like to thank Steve once again and the CDC for inviting me today.

I will be cuing everyone to advance the slide if you are doing that manually. So I hope that doesn't become annoying for some people.

So we have the front page now. We'll go to the second slide. It is a bit of a disclaimer. What I need to talk about just for a moment is that we're not attorneys here at NCHAM. Those of you on the teleconference should not take this information as what we would call sound legal advice. We have discussed many of the issues that we'll talk about today with several different attorneys. And we feel that we do have a reasonably good understanding that these issues.

However, some of the matters, especially some proposed solutions to talking through the privacy issues have not been tested legally. So we don't want to give anyone the impression to run out and do all of these things and you won't get into trouble, because you just might.

When you go back to your office and access the PowerPoint for later viewing, there may be attorneys in your agency or in your government that would take a different opinion on some of these recommendations.

I want everyone to use this presentation as general information. And where you can, apply some of the recommendations that we suggest. However, you should make sure that you've examined what is happening in your state and see what your agency's attorneys have signed off on and make sure before you put them in place.

A little on what we did to examine these issues. NCHAM, working closely with maternal and child health did a survey of all 50 EHDI programs, and then we brought together a work group of EHDI program directors and Part C program directors.

The work group were those people from states that seemed to have the most success in dealing with these privacy issues. We were able to identify potential barriers as well as some strategies for navigating these issues. PowerPoint slides, there's a set of them on the NCHAM web site and they can be downloaded as well as a paper that we've developed for mass distribution. You can go to the NCHAM web site and also get more material.

So let's go to the next slide.

Just as a matter of review, these are three primary privacy laws and regulations that we'll discuss. HIPAA, FERPA and the Part C regulations of the Individuals with Disabilities Education Act or IDEA.

Of course, Part C deals specifically with provision of services to children with disabilities who are birth to age 3. Regarding HIPAA, the Health Insurance Portability and Accountability Act, most of this doesn't focus on privacy issues. Only a small portion of it does.

Title 2 is the privacy rule that concerns us, because we want to share information with different entities. It deals with protected health information used by covered entities and we'll talk more about what covered entities are. Basically means anyone who wants to comply with HIPAA. Many people aren't really covered entities under the law, because HIPAA isn't relevant to them.

The second law is the Family Educational Rights and Privacy Act, or FERPA. It covers anyone who receives federal funding for education. Our focus is the confidentiality of the educational records.

And in our cases, the records have been decided by the court that anything that the education agency holds. It may be health records, if the education agency holds those records; it is considered an educational record and falls under FERPA. Most importantly is the Part C portion of IDEA, which deals again with birth to 3 early intervention.

Part B deals with ages 3 through adult. Part C incorporates everything that part B does, but goes a bit further. If you meet the requirements under Part C, then you've met the requirements under Part B.

Let's move on to the next slide. We'll talk about each one of these.

Let's start with HIPAA. Give you a chance to read that slide a bit. A covered entity is a health plan, a clearing house, or a health care provider who bills for provision of services. "Conducts financial and administrative transactions electronically." That part can be confusing to people.

What this really means or how it's been interpreted, anyone who bills for the provision of health care services. That's going to be a covered entity. So departments of health may be a covered entity in some of their services, but in other activities, they wouldn't be considered a covered entity.

The fact is, if you're providing health care services and you're billing for them, then under HIPAA, you would be considered a covered entity.

Then you have the term "protected health information." This is individually identifiable health information transmitted or maintained. So if you send it or if you have it in your files, then that would be considered protected health information. So HIPAA requires signed consent for anyone using protected health information for marketing or research, which is very narrow. Signed consent is not required for health care providers to exchange information for treatment or health care operations. In other words, audiologists or speech language pathologists or physicians can exchange information under HIPAA.

So to share information that allows for the health care patients, providers don't really need to get signed consent, but they need to keep a record of the information of what has been shared. So you can't forget that. Of course, signed consent isn't required if there's some public health interest, such as health tracking records.

So that's basically what HIPAA says.

Let's move on to the next slide. Take a moment and look at that.

For FERPA, it says that signed consent is needed for programs with Department of Education funding, or U.S. Department of Education funding to share any educational record with personally identifiable information. So now we have a new term.

Under HIPAA, we have protected health information, and it's really early intervention, the same kind of information essentially. If the program receives any federal funding from the U.S. Department of Education, such as public schools or perhaps day-care centers, then they have to abide by FERPA. As soon as the school has the information about the health of a child, then it is considered a part of that child's educational record. It is personally identifiable information and falls under FERPA. It's not needed to disclose general contact information, enrollment status, or attendance or in the case of health and safety emergencies.

So what does that mean?

All of you have seen situations in the local newspaper where you've seen students listed. Their names listed who have received scholarships or listed on the honor

roll. That can be done, even though it is personally identifiable information. A school can do that, as long as they notify parents at least once a year, annually, of their intention to make that happen, List that publicly. Parents do have the option to decline having their child's name listed in those kinds of things.

Many people have thought that FERPA is a major issue, especially trying to share information about infants and toddlers with hearing loss. It hasn't been the issue really. It has actually been the Part C privacy regulations that absorbs FERPA, but then goes beyond those regulations.

So let's move on to the next slide and talk more about Part C privacy regulations.

As we mentioned, Part C privacy regulations is really a little more restrictive. It says that signed consent is needed for Part C to share information with a participating provider. And this is the key phrase, nonparticipating provider.

And there is no clause in Part C, like there is in FERPA, that says that you can share certain types of information if you publish it once a year. So what Part C did was to remove that, and it became more restrictive. In terms of participating providers, that agency has to go beyond simple child responsibilities. They must provide a range of services to be considered a participating provider.

If the EHDI program is simply recording those children who fail hearing screening as a part of the child find efforts, they would be a nonparticipating provider. And signed consent would be needed to share any information back to the EHDI program.

But in some states, the EHDI program has been defined as providing a range of services and has been granted, that program has been granted a participating provider status. And in those cases, signed consent isn't needed to share information between the programs.

Some people may believe that they can't refer a child to Part C. Perhaps because of HIPAA or FERPA. But that's a misunderstanding that is more common than we'd like to see. Anybody, an EHDI program or an autism program or any program at all can pick up the phone and call the Part C intake person and say there's a child that I think needs services. You can give name, contact information, and the reason for that referral. There's no restriction on making the referral to Part C.

Signed consent is needed to share the information from Part C back to that program. Again, if that program is a nonparticipating provider.

So the Part C privacy regulations are really more restrictive than what we've seen with HIPAA and FERPA.

So let's go on to the next slide.

Look at that and let's talk a little bit about state laws. Another issue we've discovered is really what state laws say. In some states, you may have reporting laws for EHDI programs or other laws for reportable diseases. And those laws may dictate that you must share information without detailing how signed consent is handled. This could get you in trouble. State laws can make these procedures more restrictive, but they can't

take away the restrictions set forth under Part C or any federal law. So state law can't remove any of those restrictions or requirements that a federal law has put in place. They can make them more restrictive, but not less.

And we see that because of some of the laws that are out there in various states, we see that states are urging more reporting. That is a very positive thing. But again, state laws can't take away a right or protection guaranteed under federal law.

I know that can be confusing, but make sure that any type of law or policy that is put in place by your program doesn't do that.

Let's move on to the next slide.

To get an idea of how people in the field were perceiving some of what we were doing, we did a survey of all the state EHDI programs. And the question we asked was to what -- what degree does HIPAA currently cause problems or create obstacles for the EHDI program. And according to the law, HIPAA shouldn't create any programs for EHDI.

But we have a fair number of people who are saying that HIPAA is creating minor to moderate problems. With EHDI's association with hospital screenings, follow-up screenings, diagnosis, early intervention, and linking with the medical home. This underscores what the real issue is with HIPAA, FERPA and Part C privacy regulations, not what the laws actually say, but what people perceive or think they say. And so perception becomes reality.

So there are a lot of cases where people are saying, we can't do that or we can't refer because of HIPAA or we can't contact this program because of FERPA. And it really simply isn't the case.

So let's move on to the next slide.

This slide we looked at FERPA, and to what degree does FERPA cause problems or create obstacles for EHDI. FERPA, on the other hand, there's a similar scenario, except there are many more problems. We broke this down in terms of sending information to the Part C program, getting information from Part C early intervention program, and getting information describing services regarding children with hearing loss. There's no restrictions under HIPAA, FERPA or Part C about sending information to early intervention.

But as you can see, some, and even up to 5%, says there are serious problems.

9% had major problems and 18% minor problems. Again, part of what we need to do is do a better job of educating the people who are program administrators or service providers of what these laws actually say.

Again, in these situations, it shouldn't be a problem with actually getting these people referred, but we see that for whatever reason, there's a perception that these laws are preventing the referral.

So the next slide we asked how frequently are each of the following entities notified when a child fails their final hearing screening. We've got the child's primary health care provider, the child's family, the Part C early intervention program, family

support organization, and the EHDI program. You see those listed there. About one to 4% of children fail their hearing screening, depending on the system that you're using.

It's important to keep in mind that the Part C system is serving a little less than 2% of that population. If you're notifying the Part C system of every child failed the hearing screening, it would double the case load. Part C is already a system that's overloaded and underfunded. So we need to be careful about how we do this.

Some states are notifying Part C at this point in the process and they're doing a great job of tracking these children and making sure they're finally diagnosed, but maybe that's not the magical answer of how to do this. If you look at the child's primary health care provider, it says that 70% of the time the child's primary health care provider is notified of the child's failing the second screening. That's in the far left column there. The far left bar. That means that in over 25% of the cases, the primary health care provider isn't notified. They're not getting information back that the child failed their final hearing screening.

So it isn't HIPAA, FERPA and Part C causing the issue in lack of information, it's simply that we've not developed an organized system to get the information where it needs to go.

Now, you'll see that family support organizations in sort of the purple bar on the far right are rarely or almost never notified that a child has failed a final hearing screening. In some states, the family support program may be a contracted part of the EHDI or the Part C system, and sharing information with them under those circumstances could be allowed. In other states, that's probably not the case. So families often are not being told of those family support organizations because of some of these laws and the need for signed informed consents.

Let's go to the next slide.

Here we ask how frequently are each of the following entities notified when a child is diagnosed with a hearing loss. Here we're talking about when a child is actually diagnosed with a hearing loss.

On the first one we see that 98% of the time the child's parents are notified. That's a good thing. What troubles us is that in 2% of the cases, the families were not notified. So that's a little troublesome. Seventy-one percent (71%) of the time the child's primary health care provider was notified. That's good. Room for improvement. Then 47% of the time, the Part C early intervention program was notified. Now we're starting to get some data that there's a serious issue with loss to follow-up.

They're just not making it to Part C. Again, this is after the child has been diagnosed with a hearing loss. Only 50% of the time is the state EHDI program being notified. That says when an audiologist diagnoses a hearing loss, information isn't getting reported back to the EHDI program. In some states there may be specific requirements to mandate that reporting, but it appears that about half the time audiologists aren't reporting back to the EHDI program. That is a problem. Only 19% of the time our family support program is being notified. This is in part a result of the type relationship the family might have with the state system.

Let's move to the next slide.

The next slide we have to question who notified the baby's primary health care provider about the results of the hearing screening. It's got to be different in different states. Sometimes it's the hospital. Sometimes it's the EHDI program. And sometimes it has to be -- or it turns out to be the child's parents or the care givers. Part of the problem that we see with the health care providers not being notified as frequently or as consistently as they should is because in some states everyone is responsible for notifying the physician, which really means no one is taking full responsibility for notifying the primary care physician or the medical home.

So what most states need is some very clear rules, procedures, reporting processes for notifying the medical home. We think that would really help us put in place a more seamless system in most states.

Move to the next slide.

Then we ask when does the EHDI program notify Part C early intervention about an individual child? Notice that in 28% of the cases, EHDI never or rarely informs the Part C program. That says that for about 12 or 13 states that responded, they never notified the Part C program. That's one of the issues that we need to start tackling in those states. And about 22% of the cases, EHDI notifies Part C, failed the hearing screening test. Some say that's too early, because a diagnosis hasn't occurred. And others say that it is an appropriate time to notify Part C. I don't know if we truly know yet what the ideal situation is, depending on the nature of the system in the states, but based on these results, there's considerable variability among states in terms of when Part C gets notified about the child's hearing loss. About 54% of the time Part C is notified when the child is diagnosed with a permanent hearing loss.

Let's move to the next slide.

Then we asked how often does Part C early intervention notify EHDI when individual children are enrolled in Part C early intervention services. This is the other part of -- this is what EHDI programs are most concerned about. EHDI program will say that we refer children over to the Part C program, but it's like this big black hole. We never hear back from them. Never know if the children really got services or not. A few states in a few states, about 9% of the respondents, say Part C does notify the EHDI program almost all the time, and that's great to see.

But if you look to your right where the circle is, EHDI is rarely or never notified what happens to the child once they enter the Part C program. The reason that happens is that HIPAA prevents it, or in some cases FERPA or Part C privacy regulations can prevent it, depending on the situation.

So if we move on to the next slide, consent obtained in order for the EHDI program to get information about an individual child. So we asked specifically about signed consents here. As you can see, signed consent was obtained in some circumstances where it wasn't needed. Again, we see a great deal of variability how these laws are be interpreted across states.

Let's move on to the next slide.

What we want to do now is sort of talk about -- now that you understand all of these privacy laws and regulations and are experts in all of that, we'll use the various

components of the typical EHDI system as a context to discuss each one of these areas. Early intervention, medical home and other health care providers and family support programs. We want to take that model of EHDI and look at how each one of these laws or regulations applies to them.

Move to the next slide and start with hearing screening.

So hearing screening happens almost always in the hospital. About 98% of children in the United States are born in hospitals. There are different protocols. Some states use a one-step screening protocol. Others use a two-step. There are situations where the hospital may contract out to a private agency to provide those services in the hospital. After this child failed the screening, the information to be passed along to the parent, the EHDI program and possibly Part C programs

So, how does HIPAA affect that process? Well, actuality, HIPAA shouldn't affect that at all. There's no written consent needed for a hospital or other health care provider to share screenings with anyone else, especially when it's for the public health activity or ongoing health care of the child. We do have to document what you're doing. If you are sharing that information, there should be documentation about where it's going.

Now, what does FERPA say? It's really not applicable in this situation, because the children going through a hearing screening process, these children aren't known to an educational agency yet. Especially if we're talking about newborns.

Same thing with Part C. However, if you share information with Part C, the minute you share the information, they become governed by Part C. That is, Part C will need to get signed consent to share information back to the EHDI program. As we've mentioned before. Once Part C knows of the child, then Part C can't share the information with a nonparticipating entity.

Let's move on and talk about diagnostic evaluations.

With diagnostic evaluations, in some cases, a hospital may have their own diagnostic evaluations on audiologists employed at the hospital. In some states they're given a list of audiologists and told to go and find someone. In some states, there are diagnostic centers where families can be sent to. And, the family has the right to object. But almost no one does that. No family is going to say, I don't want to get that done, although there are certain cases where that does happen. So those centers are managed by the state programs.

So as you can see, depending on the situation, families can get into diagnostics or a diagnostic system in a variety of ways, depending on the state. How does HIPAA apply any of that?

HIPAA isn't needed when the health care provider shares diagnostic information with EHDI or with other health care providers or with Part C, because this is for ongoing public health activities or for the health care of the child. Diagnostically, we share that information. FERPA will require consent for educational agencies to share any individual diagnostic information with nonparticipating entities, unless you're a part of that general exception. Part C takes care of that exception, because Part C requires written consent whenever you share diagnostic information with a non-agency or entity.

Remember, that a nonparticipating entity is someone who isn't playing a major role in providing a range of services to the child. I realize that can be a little confusing.

Let's move on to the next slide.

More specifically about early intervention services. Early intervention services generally doesn't apply for sharing information among the EHDI stakeholders. HIPAA is basically irrelevant at this point, however, it would be really nice if health care providers were always a part of the individualized family service plan or the team IFSP team or the IEP team for the Part B. Federal law requires every child has one unless the family opts out of the service. For a child with hearing loss, it would be great to have a range of professionals on that team of primary health care provider, an audiologist, physical therapist, the list could go on, and they could come from different settings and different agencies.

This is a team that manages the services, and so theoretically, HIPAA, governing process could play a role, depending on the child and circumstance. If you have those different medical professionals coming from different agencies to be on an IFSP team, there is a chance that you have to get signed consent.

For FERPA, again, it says that written consent is required except for the general exception when the name of the child is on the honor roll, have parents' permission to do that. Educational agencies could publish the same list of child under age three, except for Part C goes beyond FERPA. It says, no, you can't do that. Really, Part C is the issue here, and the privacy regulations there. Again, it says if you wish to share information with a nonparticipating agency, you have to get written permission.

And this comes back to our core values. We want families to know who we're sharing information with. Some states have designated EHDI programs as the participating agencies or entities. This allows sharing of information more easily. That is particularly easy to do if the EHDI program and the Part C programs are within the same division within the state's department of health, of course, but some attorneys have explained to us just because both programs are in the same division doesn't mean that one can be designated a participating agency. It could be considered a participating agency if they have a memorandum of agreement between the two offices that uses the words participating agencies or participating entities and also to put that in the state plan, which is required by Part C to file every three years and specifically describe how EHDI helps Part C as a participating agency and thereby goes beyond the typical responsibility. If you have those things in place, the likelihood of you being considered a participating agency goes way up, even if that is legally tested.

So let's move on and talk about medical home.

For the medical home and other health care providers, HIPAA says the information can be shared among health care providers when it is promoting and ensuring ongoing health care; almost always, or if it's needed for public health activities. You have to document what information is being shared. For FERPA, again, consent is required for educational agencies to share health care providers, what we see in many health care providers, such as the physician and audiologist will say they often send report and other information to the school or to the educational provider and they would never hear

anything back from the school. So many of them just stop sharing or stop sending that information. FERPA would allow that kind of sharing back and forth, but Part C doesn't. Part C states that you can't share information with health care providers without written consent. So unless a doctor is a part of the child's IFSP team, he or she wouldn't know the information coming back. There's really no way around that exception for written consent. An individual doctor can't be considered a participating agency; at least we've not been made aware where that has been the case.

So really the participating agency designation that allows us to share information between Part C and EHDI and an identify doctor wouldn't be designated with that. So entities have legally received Part C information must abide by privacy regulations when sharing information with others. This is where people sometimes get tripped up. Part C program sends information to the EHDI program in a different division. They may have written consent to share that information, but if the local health care provider the EHDI program seeking information, the EHDI program couldn't release that information without written consent. Once a child is within the Part C program, everyone who has access or wants access to that information must abide by those restrictions.

So I know that's all a little confusing, but you have to understand what the regulations are saying.

Let's move on to the next one.

Family support programs. I think we've covered this a little bit before. These restrictions are fairly clear, as we discussed earlier, if the family support program is a part of the EHDI program, then it wouldn't be a problem. If they aren't part of the EHDI system, and in most cases they would not, HIPAA would restrict the information that would go to the organization.

Part C would restrict that even further. The family support program is considered a participating agency and getting information back and forth isn't a problem. In some states, the moment when an EHDI program knows of a child with a hearing loss, then the family support program is notified because they are a part, of a participating agency within the EHDI program and also Part C would be notified.

So if all three are participating agencies, then each one has the information that they need. As you can imagine, this isn't happening in many states, only a couple. There's a great deal of ground work to be done to make sure that become a seamless system where information can be shared back and forth.

For the sake of time, we'll see the next couple of slides the next slide will be of the NCHAM web site.

You'll see we have several items listed related to what we're talking about today. And if you go to infanthearing.org and go through the PowerPoint and some other valuable tools that have been posted from some of states.

For example, some of the legislation, memoranda of agreement, we're calling some coordinated referral forms. I'll talk about that in just a moment, the recommendations. You can go to the web site and track down that information and download everything you need. I would invite all of you, if you have forms and

legislation and processes that you've worked out that have worked very well in your state between agencies and making sure the services are more seamless, this you'd like to share them with us at NCHAM and we can post them on the web site, I'd ask you to send that to us.

Let's talk about the recommended strategies. The first recommended strategy is there needs to be education of the family. They understand that their medical records belong to them. The easiest way to make sure that information is shared and to education the families to get copies of their own records and they can share the information with whomever they want to, parents also need a copy of the various consents they have signed, which comes to the next point. We really need a coordinated set of consent forms.

The fact that we get parents are complaining that they sign the same consent form 102 times to get basic services, and that really shouldn't be the case. There are a couple of states that have developed some common consent forms, and we have good examples on the web site. Look under that tab of coordinating consent forms. And you can get that information.

Next is a memorandum of agreement. In the hearing screening world, when a child fails a hearing screening, the family would sign a consent form that would allow that information or any subsequent information to be shared with physicians, with the EHDI program, the family support program, and back again. A few states have done that. Some states have done it quite what we would call in a complicated way, and other states have taken a more simple approach. If I were going to do that, I would probably start off and try something very simply, get some kind of document in place that can be shared, and then see how it can come together.

The memorandum agreement between the EHDI program and Part C, and Family Support Program would be an attempt to create that participating agency designation. You have this outlined in the state plan, and it's going to be a lot easier to share that information between entities. If you have that listed in the state plan and those MOA's are in place, that has been accepted at least so far, having that designation and having a MOA and listed in the state plan, and that scenario has been accepted as sort of justifying or adding credibility that that EHDI program or that program is indeed a participating agency.

But that has to be outlined. There has to be documentation that you are working together and that memorandum of agreement would allow that to happen. So the last point is to encourage you to look at the EHDI program and see if it fits. In some cases, the EHDI program may not be considered a participating agency, because it does not go beyond the child find. You have to make sure EHDI is doing more than just reporting names for child find.

Let's move on to the next slide.

The next recommendation, number five, would be state laws. State laws that require reporting are very good, but remember that they cannot take away any of those protections that are guaranteed under federal law. So everyone will agree that if you have a state mandate or a state law, that will certainly encourage better sharing of information between agencies and the collection and sharing of data and information between

agencies, but you have to keep in mind that any state law can't trump what the federal law says, if there are strict guidelines at the federal law, you have to make sure that you're dealing with that in the state laws too.

Number six; obtain written permission from parents as a part of IFSP/IEP document. This is something that's different and kind of novel. If a parent participates in those meetings, it would be great to have some port of those documents designed to be shared with multiple agencies, again, some type of coordinated form. Although this would sort of go beyond that. So this is maybe just pie in the sky, wishful thinking, but it would be great if we could somehow put that in place, so when everyone is together at those meetings to share information.

So the next one integrated computer-based public health information system that are designed to share information would be a big step in the right direction. We've had lots of success sharing immunization history, blood spot screenings in a number of different areas. We've had success, but it takes a great deal of work coordinating multiple agencies and sometimes multiple computer systems to get them to communicate with each other. Some states are doing a reasonably good job at that. And other states are still struggling. But I think we do need to really work on developing some coordinated data tracking systems that go beyond just EHDI, but EHDI systems to get these things tracking.

In summary, we have to find ways to have greater communication among these various agencies and programs so that families and children can get needed services in a timely manner. People have been paralyzed by HIPAA and FERPA. What we needed to is to take a look at some of these states where they're having some success and see what can work in more states. Whatever we can do to make sure the parents are better informed, whatever we can do to coordinate consent forms so that they're aware of the continuum of services, and whatever we do to encourage agencies to become participating entities, those are the kinds of things we need to do to break down these barriers and help children and families get to the services that they need and deserve. So with that, I'll open up for questions. If you have questions, feel free to e-mail me or give me a call here at Utah State University. If we have some time left, I'll be glad to try to answer questions.

>> CALLER This is Hallie Morrow from California. I guess my question is what are the implications of becoming a participating agency for Part C, what does that obligate the EHDI program to do in terms of IFSP activities, complaints, or if there's any disputes between what the EHDI program can provide versus what Part C should be providing?

>> Todd Houston: I think you have to go back and look at the range of services provided by the by a participating agency. Again, you have to go beyond just simple child find activities. Many EHDI programs are doing more than just child find. Some are getting into some service coordinating and some other areas. So legitimate early intervention, they could be labeled as a participating agency or a participating entity. Unless you're providing direct services in terms of early intervention, in most case EHDI is not going to provide early intervention services. I don't think you'll have to

worry about the IFSP situations where you have to go in and state goals and attend those meetings.

>> CALLER: You're saying you can be a participating agency and not be identified in the state plan?

>> Todd Houston: It depends on what you want to do. It kind of depends on the state as well. With the IFSP, it is really the service plan for that child and getting early intervention services, and so I don't know if many programs that are providing direct services in that manner as traditionally defined under Part C. That's usually done by the Part C early intervention program. I don't think the EHDI program would be responsible.

The goal of becoming a participating entity was so that you can get information to track those children to know what happened to them.

>> CALLER Okay.

>> Todd Houston: That's the major reason that I would say, let's work at getting more designation -- EHDI programs designated as a participating entity so you can track those children. That's the main goal.

>> CALLER Okay. Thanks.

>> CALLER This is Mary Katherine in Texas. I wanted to ask a question. When you're talking about the concept of a child find, if an EHDI program was mandated to do the screening, how is that not doing more than child find only, and how do you differentiate that from being a covered entity or whatever the term was?

>> Todd Houston: The covered entity or the participating provider.

>> CALLER Correct.

>> Todd Houston: Screening is a child find. If you look at screening in other areas, other health care areas, screening works on identifying individuals that get put into a system, and that's a simple definition. So you have -- the EHDI program would have to go beyond that and be able to really document what they're doing.

So, Mary Katherine, so you would have to go beyond screening and also provide service coordination or other type of service that was being provided beyond just identifying that there's a child that is at risk.

>> CALLER Okay. I think that sort of helps clarify. If an EHDI program was doing diagnostic services as part of its service, then it would be potentially part of the participating provider; but if it's just doing screening, it's only doing child find. Is that correct?

>> Todd Houston: That's how we interpret the law in terms of how it's worded. Again, some states have designated the EHDI program as participating provider or a participating entity. In some states it's been approved and accepted. I think there's opportunity there for more states to investigate that and see if they can't make that happen.

>> CALLER Thank you very much.

>> Todd Houston: You're quite welcome.

>>CALLER This is Ellen from Rhode Island. If you look at your slide that talks about FERPA.

>> Todd Houston: Okay. I'll look back.

>> CALLER Okay. In the beginning part, it says signed consent is needed to share an educational record. And that would include any hearing screening or hearing testing that was done in the schools, et cetera. And then you say, signed consent is not needed to disclose the general information, but you have to do an annual notification about the intent to share the general information.

I've had something, and I acknowledge that you're not providing legal advice or anything, but just want to know if you've heard of this. I've had people interpret that you need a signed consent annually. Is that accurate or can you -- when a child registers for a school, can they say they sign once saying yes, it's okay to share school hearing screening result with whoever? Or does that have to be done annually?

>> Todd Houston: What the law says is an annual notification of intentional to share. I know not long ago, or last fall, we registered my children at a new school, and they had all of those forms and they did that, a little waiver in the front of the parent handbook saying this is our intention and this is what we do as a matter of process at this school. And if you -- here is how you can opt out of it. But this is our intent. So that is sort of what the law says, that the educational agency has to provide that annual notification that this is the intention. And then parents can opt in or opt out. Or they can opt out if they don't want their child's name shared for those purposes. Then they have to sign a different form.

>> CALLER That's for the general directory types of information?

>> Todd Houston: Yes. That is more general directory, scholarship letters and honor roll types of things.

>> CALLER If you had signed a consent when you signed your child up saying I am comfortable with the school sharing school hearing results with the EHDI program, would that signed consent have to happen every single year?

>> Todd Houston: My understanding of the law, because then you're talking about two different agencies, in a sense. You're talking about under FERPA, which is -- that becomes -- the hearing screening is done on school grounds by the school district, then that is a -- then that will fall under FERPA. If EHDI is not a part of that system, then you would need signed consent in those instances.

>> CALLER Annually or once?

>> Todd Houston: They can sign a consent -- when you got ready to send that over. How often are you talking about sending screening?

>> CALLER If they screened annually, they would have to get it annually?

>> Todd Houston: I would designate typically in that signed consent process that the hearing screening would be sent to the state EHDI system and your signature is required.

>> CALLER Once or every year?

>> Todd Houston: I think you'd probably want to do that each year.

>> CALLER That's what makes it so much harder to apply. It's every single year.

If you can do it on school entry, when they register for the school, it's easy. But if you have to do it every time they get their hearing screen, it becomes more cumbersome.

>> Todd Houston: If there was a form that could be developed, and I don't know if anyone has done this, at the IEP meeting, you know, that here is the releases we're going to have, this is going to be good for three years.

>> CALLER These aren't IEP. This is just the general population.

>> Todd Houston: Okay. These children couldn't be necessarily in special ed or getting though service. It's a conundrum. I would say, my best legal knowledge at this game is you would need, based on my understanding of it, a signed consent each time you want to send that. Hopefully, you could do that in a way where it's fairly straightforward at the beginning of school that everyone signs it. If the child ends up having a hearing loss, it is automatically referred on.

>> CALLER Right. Thank you.

>> Todd Houston: Thank you. Good luck.

>> Steve Richardson-CDC: Thank you, Dr. Houston, for your presentation today.

[End of teleconference]